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### Beyond stroke

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# Beyond stroke: Description and evaluation of an effective intervention to support family caregivers of stroke patients

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## Abstract

**Objective:** The objective of this study was to evaluate the strengths and weaknesses of a group support program and a home visiting program for family caregivers of stroke patients. It also examined the best fit between intervention variant and family caregiver and patient characteristics. van den Heuvel's previous effect study showed positive effects of the same intervention program, but unlike our present study differences between the two support variants could not be measured.

**Methods:** Of 257 family caregivers who were included and randomly assigned to an intervention variant or a control group, 127 family caregivers completed the intervention in either the group program or the home visiting program.

**Results:** Evaluation data showed that both intervention variants had been helpful and feasible, but home visit participants missed peer contact and follow-up contacts were missed in both intervention programs. In comparison to the home visiting program, the group program participants showed more benefit especially with respect to informational and emotional components. Caregivers' preference for type of intervention revealed that both types of intervention had its supporters. Those that preferred the group program could be clearly characterised: they were burdened, lived with a more psychologically handicapped relative, were using active coping strategies more frequently or lived in a region which is considered to be more sociable.

**Conclusion:** The present study adds extensively to van den Heuvel's effect study with respect to discriminative aspects of group and home intervention programs and their respective benefits for specific family caregiver groups.

**Practice implications:** In order to suitably match an intervention type with specific caregiver characteristics the intervention provider should utilize caregiver self-selection or undertake professional screening of caregiver burden. Telephone contacts should be offered in addition to the interventions.

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**Keywords:** Family caregiver; Stroke; Individual support program; Group support program; Intervention; Evaluation

## 1. Introduction

Family caregivers of stroke patients are seriously in need of support. In both the short and long term, many family caregivers report physical symptoms and psycho-

logical distress as a result of giving care. This often leads to social isolation and burnout. Many family caregivers feel responsible for home care as a consequence of their kinship with the stroke patient. Family caregivers may not be aware of their care-giving role and those that are aware often complain that they are not properly recognised as a caregiver by the professional health care workers [1–5].

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In the Netherlands around 50,000–60,000 family members provide care for stroke patients at home. Most are female spouses of the patient and are elderly themselves [6]. Approximately 30,000 people are annually afflicted with stroke in the Netherlands. It is estimated that 120,000–140,000 people in the Netherlands have suffered one or more strokes [7]. Due to increasing ageing of the population it is estimated that the incidence of stroke will increase by 30% in 2015 [8]. The prevalence of stroke survivors will increase as a result of more effective treatments and a decline in mortality [9,10]. Changes in the health care system have resulted in a shift of care from in-patient organisations to ambulatory or home settings. These trends will lead to an increased need for care of stroke survivors and a greater need for family care giving. About 80% percent of stroke survivors return home after initial hospitalisation and stroke rehabilitation. These patients rely on their family members' emotional, informational and instrumental support for daily living [11].

Availability and training of family caregivers of stroke patients have a considerable impact on professional care delivery and health care costs reduction [12]. In the Netherlands family caregivers can rely on assistance from home care nurses, general practitioners, speech therapists and voluntary help – for example: meals on wheels, transport and patient attendant functions. More recently, informal regional centres were set up to provide caregiver support and to give caregivers information and advice on caring for the patient. More intensive caregiver support education is offered by organizations for home care nursing and by the National Heart Association.

A review study on the effectiveness of interventions for stroke caregivers demonstrated a variety of types of support programs; contents, objectives, objects (patient and/or caregiver) and the timing of implementation (acute of chronic phase) all varied. Most intervention effect studies had the patient's outcome as a target goal, whereas Visser-Meily et al. advised that support programs and interventions should aim to minimise family caregivers stress and focus on caregiver problems. Counselling programs appeared to have the most likely positive outcomes [13].

The randomised controlled intervention effect study of van den Heuvel et al. aimed to counsel and educate family caregivers of stroke patients. Their study showed positive effects in knowledge about patient care, self-efficacy, and the use of active coping strategies and social support. Differences between group support and individual support programs could not be measured in their study [14,15]. The support intervention was based on the stress-coping model of Lazarus and Folkman [16]. This theory along with other literature findings indicates that knowledge and coping are important factors for family caregivers' well being, since they are thought to buffer the impact of stressors [17]. Two intervention variants for family caregivers were developed and tested: a group support program and an individual support program at the patient's home. In the Netherlands no

evidence was available to show which type of program offers the greatest benefit to family caregivers of stroke patients. Both intervention types differ in the extent to which 'social comparison' could be practiced [18,19]. Findings of Toseland and Rossiter [20] showed no clear correlation between participants' subjective evaluations and the more objective effect measures. This finding suggests that using evaluation data for a deeper analysis of differing intervention components might reveal additional knowledge on this subject as compared to effect studies.

In the present research evaluation data from van den Heuvel's intervention effect study will be analysed from the viewpoint of the participants in the support programs. The focus will be on the relative strengths and weaknesses of both intervention types and in addition, we aim to characterise those family caregivers which are more likely to benefit from a group program versus a home visiting program.

The research questions to be answered in this study are:

1. How did family caregivers evaluate the intervention they participated in?
2. Which aspects of support were helpful?
3. Which characteristics of family caregivers' and stroke patients' correspond with the caregivers' primary preference for type (group versus home) of support program?

With respect to research questions 1 and 2 the intervention will be described in more detail in the methods paragraph.

## 2. Methods

### 2.1. Recruitment and inclusion of participants

The subjects of this study were family caregivers of stroke patients. The family caregivers were eligible for inclusion in the study if: (a) they were the main caregiver of a stroke patient living at home; (b) the patient's first stroke had occurred between July 1992 and July 1996; and (c) the patient was >45 years at the time of the first stroke. To minimize the chance of family caregivers having fully adapted to their care giving role we choose a period half a year to 3 years from stroke onset. The medical ethics committee of Groningen University Hospital approved the study. Family caregivers were recruited through general practitioners, hospitals, home care services, rehabilitation clinics and the media in four regions of the Netherlands between February 1995 and June 1996. During this period professionals were approached and asked to inform stroke patients' family caregivers who met the inclusion criteria about the intervention and the research project. If caregivers were interested, the professional health care workers gave them a special leaflet describing the intervention and the

research project. An enrolment form was enclosed with the leaflet. Family caregivers willing to participate were asked to mail the completed enrolment form to the researchers. On enrolment in the study caregivers did not know in which group they were to be allocated. When their enrolment form was received, the family caregivers were assigned to either the group program, the home visiting program, or the control group in blocks of 8–13 caregivers. We planned to assign about 100 participants to each condition. For the group program we succeeded in doing so, but after assignment of the sixth block the number of participants who signed up for the study decreased, and the recruitment-period at that time was too short to accomplish assignment of 100 participants to the home visiting program and the control condition. This resulted in 130 participants being assigned to the group program, 78 to the home visiting program and 49 to the control group.

## 2.2. The intervention

This section starts with a summary of the educational and structural aspects of the intervention variants in Section 2.2.1. Secondly, in Section 2.2.2 the program contents are summarized and illustrated with examples. Finally, the implementation of the programs is dealt with in Section 2.2.3.

### 2.2.1. Educational and structural aspects

The following educational aspects were selected for the program due to their known effectiveness, along with provision of support for participants' learning.

- The intervention should contain a combination of education and counselling [21].
- The intervention should be based on 'learning by doing' [22].
- The intervention is most appropriately targeted at participants who share certain characteristics [23].
- The intervention should contain a fixed component including a predetermined number of sessions and implementation intervals, as well as a standardized program manual, and a flexible component incorporating individualized themes based on participants priorities and problem areas [24].
- A multidimensional approach to assessing and dealing with problems was decided upon, focusing upon emotions, information and coping [13].
- A balance was sought between attending to positive and negative aspects of the participants experiences [25].

Structural aspects of the intervention:

- The group and home visiting programs differed in duration and location. The group program comprised eight 2-h sessions with 8–12 family caregivers who met at the office of the home care service in the nearest city,

while the home visiting program consisted of four 2-h sessions with the family caregiver and the patient at the patient's home. Each program lasted 10 weeks. As a result the time intervals between the four home visit sessions were greater than those of the eight group sessions.

- In both programs each session followed a fixed schedule: introduction of today's topics, looking back on home exercises, exploration of participants' questions, problems and advice about the themes of the session. After the introduction, a participants' case study was selected and analysed using a standardized problem solving method. In the group program all participants took part in practicing problem solving steps in an illusive way. Subsequently, homework was set to practice problem solving in 'real life'. During the case study delivery of information, skills, emotional expression and exercises were addressed. The session ended with a short evaluation of the session by the participants followed by a homework assignment.
- The intervention types were equal in content and use of counselling and education strategies for helping family caregivers to deal with emotional and practical problems, especially those related to a balanced lifestyle and role changes.
- Separate intervention manuals were written, for guiding the group program and the home visiting program. Each manual contained a theoretical paragraph, a script for every session and appendices [26a, 26b].
- Experienced home care nurses educated to degree level implemented both programs.

### 2.2.2. Program contents

Table 1 shows the content of the intervention program sessions. The topics and themes are identical for the two program variants. During one session of the home visiting program it was possible to cover the equivalent content of two group sessions. It was hypothesized that home visits could focus more directly upon the problems at stake.

### 2.2.3. The implementation process

The program was implemented by 17 experienced home care nurses educated to degree level, working in paid employment in home care organizations in three northern and one southern province in the Netherlands. The nurses—all but one was female—assigned themselves to either the group or the home visiting program. Nurses appeared motivated to undertake training and to implement the intervention. Both groups of nurses received a 1-day coaching skills training session, half of the nurses for implementation of the group program, the other half for the home visiting program. Guidelines on how to use the program manual were provided. Some parts of the intervention were practiced and discussed in a role-playing setting. For example: how to cope with family caregivers' emotions, how to train problem-solving skills, how to listen

Table 1  
The contents of the group and home visiting program sessions<sup>a</sup>

Session 1
Getting acquainted
Goals of the intervention program
Participants' expectations
What does the program offer?
Procedures
Session 2
Post stroke experiences
Discharge from the hospital and taking care of patient at home
Home again: who gave support and help?
Session 3
What is a stroke?
Consequences of stroke for the patient
Consequences of stroke for living together
Session 4
Consequences of stroke for the primary family caregiver
What useful lessons did you learn?
Session 5
Taking care of the patient
Techniques for assisting patient
Lifting techniques
Communication techniques
Social map of where to get help
Preparation for the worst case scenario
How to ask for help?
Session 6
What is stress?
Coping with stress
Relaxation techniques and exercises
Systematic coping with problems
Session 7
Stroke risk factors
How to achieve a more balanced way of life?
How to organize an enjoyable day?
Financial matters, insurance, legislation
Session 8
What daily activities do you perform?
Time management and leisure time
Looking back on the intervention
How to proceed after the intervention?

<sup>a</sup> Each home visit program session was double the length of the group program session. Therefore, the home visit programme was implemented in four double sessions, whereas the group programme was delivered in eight single sessions.

to the participants, how to encourage learning from fellow participants, and how to deal with quiet or domineering participants. During the nurse training session, arrangements were made to pair home care nurses for peer tutoring sessions. In addition, appointments were made for a meeting with trainers and researchers to exchange information and provide feedback. The home care nurses were instructed on the use of logbooks for recording session events. Logbooks were used to minimise implementation execution bias among nurses.

In order to optimise participation the travel expenses of participants were reimbursed—the program itself was free of charge. Travel expenses were also provided for home care nurses. The researchers recruited all participants.

### 2.3. Measurements and statistics

A satisfaction survey was given to participants after completion of the group ( $n = 83$ ) or the home visit program ( $n = 44$ ). The participants were asked to give their comments on the contents, logistics and implementation of the intervention using visual analogue scales ranging from 1 to 10. [27].

Caregivers completed a 'Mechanisms of change questionnaire' 1 month after finishing the intervention ( $n = 127$ ). It's five subscales elicited responses on information (nine items,  $\text{kr}20 = .72$ ), advisory (four items,  $\text{kr}20 = .60$ ), normative (four items,  $\text{kr}20 = .54$ ), emotional support (seven items,  $\text{kr}20 = .58$ ) and support in gaining self-knowledge (eight items,  $\text{kr}20 = .80$ ) components. Scores were determined for each subscale and the mean values are presented for both programs. The non-parametric Wilcoxon test was used to test differences between group program participants and home visiting program participants [27].

The caregivers' preference for intervention type was measured at baseline ( $N = 212$ ). Besides the two interventions types used in the study a third type – 'group support for 'pairs of caregivers and patients' – was also presented as an additional preference option. Chi-square tests as well as analysis of variance (Kruskal–Wallis) were used to examine whether the primary preference for one out of three types was associated with demographic variables and with characteristics of family caregiver and patient. The measurement instruments used for determining the demographics and characteristics were:

- Socio-economic status. This was measured using the occupational prestige scale with a range 1–100 [28].
- To assess the patients' physical health a subscale (29 items,  $\alpha = .87$ ) of the Sickness Impact Profile-68 (68 items,  $\alpha = .92$ ) was used [29].
- The family caregivers' physical health was measured with a subscale of the Rand 36-item Health Survey Short Form (10 items,  $\alpha = .92$ ) [30].
- The patient's psychological limitations were measured by proxy by a 17-item list developed by the authors ( $\alpha = .86$ ) [14].
- The family caregiver's burden was measured with Robinson's caregiver strain index (13 items,  $\alpha = .80$ ) [31].
- For the measurement of the family caregivers' active coping strategies two subscales of the Short Form Utrecht Coping List-15 were used: the subscales 'confronting coping' (five items,  $\alpha = .81$ ) and seeking social support (five items,  $\alpha = .73$ ), both indicate the concept of active coping [32].

### 3. Results

#### 3.1. Response

Of 257 family caregivers who agreed to participate, 130 were assigned to the group program, 78 to the home visiting program and 49 to the control group. The drop out rate before starting the intervention was 20 (15%) in the group program, 18 (23%) in the home visiting program and 7 (14%) in the control condition. The main reasons for drop out were caregivers' poor health, death of the stroke patient and no perceived requirement of intervention. During the intervention period (about 18 weeks) another drop out took

place: 8 persons (7%) in the group program, 11 (18%) in the home visiting program and 3 (7%) in the control group. One hundred and thirty-nine intervention participants were interviewed in the short-term effect study. This group consisted of 127 family caregivers who had completed the intervention plus 12 who did follow half or less of the intervention sessions and formed the intention-to-treat respondents. Out of the 127 completers 118 returned the evaluation questionnaire: 78 participants in the group intervention and 40 in the home visiting intervention. At baseline measurement the caregiver respondents' mean age was 65.3 years; the patients' mean age was 73.5 years. 73.5% of the caregiver respondents were female. The mean

Table 2

Helpful aspects in the group program and in the home visits

	"Experienced as helpful"			
	Group program		Individual program	
	Mean	S.D.	Mean	S.D.
Informational support: ( <i>n</i> = 77 and 33)	7.83	1.69	6.94	1.95**
1. Gaining medical knowledge of the disease				
2. Having a better understanding of the disease				
3. Receiving information about forms of support I can ask for if the need arises				
4. Gaining insight into what I can and cannot do for the patient				
5. Discovering that my situation is similar to that of others				
6. Receiving information about the neuropsychological consequences of the disease				
7. Understanding the cause of problems in caring for the patient				
8. Discovering what is challenging in the care for a stroke patient				
9. Seeing how others cope with problems that are comparable to mine				
Advisory support: ( <i>n</i> = 77 and 37)	3.26	1.04	3.05	1.13
10. Receiving advice and practical suggestions on how to deal with certain situations or problems				
11. Being encouraged to try new ways of dealing with problems				
12. Seeing different ways of dealing with the same problem				
13. Practicing how to deal with certain problems				
Normative support: ( <i>n</i> = 78 and 40)	3.63	0.72	3.35	0.98
14. Being encouraged to take time off from my responsibilities as a family caregiver occasionally and find time for myself				
15. Being reminded to consider myself as well as the patient				
16. Being encouraged to seek additional outside help for looking after the patient				
17. Discovering that I can rely on my own judgment				
Emotional support: ( <i>n</i> = 77 and 33)	5.97	1.26	4.79	1.62**
18. Learning that my problems are not unique and that others in similar circumstances have the same experiences				
19. Learning that there are people to whom I can turn for help, so that I no longer feel alone				
20. Learning to accept the situation of the patient				
21. Helping others who are in a similar situation				
22. Being encouraged by the successful coping of others				
23. Feeling supported by others				
24. Unburdening to someone				
Gaining self knowledge: ( <i>n</i> = 75 and 35)	5.32	2.39	4.91	2.16
25. Knowing that I am responsible for my own decisions and actions				
26. Developing the ability to discriminate between realistic and false hope				
27. Being able to show my fears and feelings of uncertainty to someone else or others				
28. Discovering why I think and feel the way I do				
29. Realizing that there are times when life is unfair and unjust				
30. Finding someone who can be a role model for me				
31. Discovering how others see me				
32. Discovering new ways of looking at my problems and trying to control my emotions				

\*\* Wilcoxon test: significance level,  $p < .005$ .



age of the intervention completers was 61.6 years, 72.2% being female. Mean level of the socio-economic status was middle class (mean score 46.0, on a scale ranging from 0 to 100). All family caregivers were spouses of the stroke patients with Dutch provenance.

### 3.2. How did family caregivers evaluate the intervention they participated in?

Evaluation of program logistics, such as duration, implementation by home care nurses, and effects of the intervention yielded generally positive outcomes. On a scale of 0–10 the overall mark for the intervention was 8.4 for the group intervention and 7.9 for the home visiting program. Caregivers frequently reported that ‘learning how to take better care of themselves’ was an important aspect of the programme. Caregivers’ comments, regarding the number and duration of sessions, relevancy of topics, organisation, style of session and management and coaching role of the facilitating nurses, were very positive. Participants were more critical of the lack of follow-up sessions. Suggestions for improving follow-up contacts included repetition of the sessions every 6 months or telephone consultations with the home care nurse. Some participants in the home visiting variant were dissatisfied with the absence of peer contacts, whereas certain participants in the group intervention

expressed dissatisfaction with the amount of attention that could be paid to their individual problems.

### 3.3. Which aspects of support were helpful for the family caregiver participants?

Table 2 shows that the group program participants did perceive certain intervention components as being more helpful than others. Informational and emotional support were found to be particularly helpful.

Which characteristics of family caregivers and stroke patients correspond with the caregivers’ primary program preference for type (group or home) of support program?

Participants’ illusive preferences were recorded prior to their random allocation to an intervention. Patients could select their primary preference from among the following programs: family caregiver group program, home visiting program, or patient-caregiver couples group program.

The primary preferences of the family caregivers are presented in Table 3.

Family caregivers generally preferred the group intervention to the home visits. Further analysis characterised the family caregivers in each preference group. See Table 4.

Table 4 shows striking differences between family caregivers with different intervention preferences. Regional differences in preferences were observed – not presented in the table – varying from 3% in one province to 42% in the other for paired groups, from 33 to 55% for family caregiver groups and from 25 to 53% for home visiting.

Being a family caregiver of a psychologically impaired patient was associated with a preference for group intervention ( $p < .05$ ). Family caregivers with higher scores on confronting and help-seeking coping strategies expressed a preference for a family caregiver group program ( $p < .05$ ) as well as for the paired group program ( $p < .05$ ) significantly

Table 3  
Family caregivers’ primary preference for type of intervention

Primary preferences for	
1. Groups support program for family caregivers	$n = 82$ (42%)
2. Home visiting program	$n = 67$ (34%)
3. Groups of pairs of family caregiver and patient	$n = 44$ (24%)
Total	$n = 193$ (100%)

Table 4  
Intervention preferences in relation to characteristics of family caregivers and patients

Variables	Relation to preference for variant			$p$ -value
	$n$	Chi-square		
Gender patient male/female	143/50	4.31 (d.f. = 2)		.12
Gender family caregiver male/female	50/143	3.08 (d.f. = 2)		.21
Regional differences in preference	193	20.35 (d.f. = 6)		.002**
	$n$	mean	S.D.	$p$ -value
Age patient	193	67.5	9.38	.164
Age family caregiver	193	64.6	10.05	.067
Socio-economic status	186	45.6	16.00	.498
Duration of stroke	193	3.47	3.96	.659
Physical health stroke patient	188	9.70	5.73	.796
Physical health family caregiver	189	16.02	4.95	.552
Psychological limitations of stroke patient	191	35.52	10.56	.002**
Burden family caregiver	193	26.07	5.86	.037*
Confronting coping behavior family caregiver	192	13.31	2.77	.037*
Coping: seeking social contact	191	9.46	2.75	.027*

Chi-square test and Kruskal–Wallis analysis of variance.

\*  $p < .05$ .

\*\*  $p < .005$ .

more often. The family caregivers who preferred a group intervention experienced significantly greater burden than those who preferred home visiting ( $p < .05$ ).

## 4. Conclusions and discussion

### 4.1. Conclusion

The evaluation results indicate several points of interest.

First, interventions carried out in both the present effect study and the study of van den Heuvel were widely appreciated by the participants as well as by the providers of the support. Family caregivers pointed out that they had learned how to take better care of themselves. Critics in the home visiting program reported a lack of contact with fellow caregivers, whereas some group participants reported a lack of attention to their individual problems. Participants in both program types expressed the wish for continued contact with the home care nurse after the intervention was completed.

Second, the present evaluation study revealed differential effects between intervention types, whereas the effect studies of van den Heuvel et al. [14,15] did not show such differences.

A third topic addressed in this evaluation is the association between family caregiver characteristics and their preference for intervention. Family caregivers who preferred the group program, were characterised as being burdened, using active coping strategies more often, living in the south of the Netherlands and caring for a more psychologically impaired patient. These 'profiles' may be useful indicators for program allocation of family caregivers in the future.

### 4.2. Discussion

Our evaluation study added new data to the objective effect measurements of van den Heuvel et al. [14,15], since the findings in the present study pinpointed differential evaluations for both intervention types. This aspect of the evaluation study also seems to confirm the findings of Toseland and Rossiter [20] which revealed that there is no clear correlation between participants' evaluation and the more objective outcomes of an effect study.

The identified differences in informational and emotional support outcomes in-group programs versus the home visits interventions suggest a positive effect of contact with fellow caregivers in the support group. This may be explained by upward comparison. Taylor and Lobel found that upward comparison can have a favourable effect on a person's emotional well-being, since contact with persons in similar circumstances who are better able to cope, might generate information which positively impacts upon one's own problem solving skills [18,33]. Such mechanisms cannot occur in a home visit program.

Preferences for a specific intervention type among specific family caregiver categories suggest that as the

burden of giving care increases due to psychological impairments in the stroke patient, there is a greater need for contact with fellow caregivers (social comparison) and for outside support. Conversely, as was indicated by some participants, a group program may offer fewer opportunities to provide individualised support to family caregivers.

The finding that the drop-out rates were highest in the home visits intervention is rather surprising, since home visits pose fewer barriers for family caregivers such as travelling and leaving the patient alone. An explanation may be that the presence of the patient during the home visit sessions may have prevented the family caregivers from disclosing their support needs.

### 4.3. Limitations

The results of our evaluation study are necessarily restricted to family caregivers of stroke patients that met the inclusion criteria. Excluded participants included the population in the middle and West regions of the Netherlands, family caregivers of young ( $<45$  years) or institutionalised stroke patients, or stroke patients for which the onset of stroke outlasted 3 years at baseline measurement. Our study sample was rather young (mean age 61.6 years) since the mean age of family caregivers of stroke patients in the Netherlands is between 72 and 78 years. Sequential randomisation techniques were used to assign family caregivers to the study intervention. Since group interventions had to be planned ahead to fit in with the course schedule of the home care organisation's blocks of participants were with greater priority assigned to the group program to attain a group size of 8–12 participants. As a result, it was not possible to meet the allocation of 100 caregivers to both intervention groups and the control group. Further, relatively more family caregivers dropped out of the home visiting program before completion. In total there was a 37% dropout in the home visiting program versus 21% in the group program and 20% in the control group. This might have negatively influenced results in the home visits arm of the study. Compared with the participants who completed the intervention, the drop outs were older ( $p < .001$ ), took care of an older patient ( $p < .001$ ), were in worse physical condition ( $p < .01$ ) and had less confidence in their knowledge about patient care ( $p < .05$ ) and self efficacy ( $p < .05$ ) [34]. Drop-out rates may have resulted in an under representation of high risk patients and their caregiver on one side and low risk patients and family caregivers on the other side of the continuum.

### 4.4. Practice implications

Since the results of this study are not fully representative of the entire stroke family caregiver population in the Netherlands, future efforts have to target the often under-exposed stroke family caregiver categories: the elderly, the institutionalised and the young family caregivers. To support



these family caregivers adaptations will have to be made in the intervention manuals, regarding their specific needs for support. The problems of family caregivers of stroke patients may resemble those of the caregivers of Alzheimer disease patients and Parkinson's disease, since the patients' cognitive impairments are a common factor, and efforts should be made to cooperate in developing and testing support interventions [2,35,36]. Non-participation and dropout during the intervention is common but not fully understood [34]. Family caregivers are often unaware that they are a 'caregiver', so it is very unlikely that they will be aware of their individual risk of burnout or support facilities available to them. Under use of support facilities might be reduced by approaching family caregivers in the early stages of stroke occurrence with information regarding support facilities and potential risks for the patient and for the family caregiver. Health care professionals should be willing to arrange for referral to a specialist who can provide information on availability of support in their area.

In relation to the psycho-educational content of our 'beyond stroke' intervention, home care nurses were found to be well motivated and provided professional coaching for family caregivers. Training and a feasible manual appeared to be the appropriate tools needed for undertaking the study interventions. It is suggested however, that better education for caregiver support should be introduced within the nursing degree course.

As a result of our evaluation study new knowledge is available for matching types of intervention with individual caregiver needs. Intervention matching might be carried out through a caregiver self-selection procedure. Alternatively a professional screening procedure might be used to select the

best program for individual caregivers by quantifying the level of burden experienced by each family caregiver (cut-off score  $\geq 7$ ). A further approach would be to create a support program combining home visits and support groups that balances individualised and peer group support. Telephone contacts with the course leader should be offered as a means of follow-up, as suggested by the participants in our study. Evidence of the positive effectiveness of problem-solving interventions via telephone is offered by Grant et al. [37]. Contacts with the regional 'points for caregiver support' and use of Internet should be promoted.

During the last decade in the Netherlands a growing interest in the crucial but vulnerable role of family caregivers in the health care system has arisen. There has been a consequent rise in financial provision for professional support of non-professional caregivers and a greater recognition of family caregivers needs. Today the intervention 'Beyond Stroke' is being implemented in several regions in the Netherlands by trained home care nurses and stroke nurses with a degree.

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## Appendix A. Two examples

### Example 1:

Example one is taken from the session 'Home again: who gave support and help?'. The goal of this session is to stimulate awareness of the social network by discussing the social support family caregivers received or lacked when the patient returned home from the hospital.

The script in the manual for the home care nurse reads:

"Introduction by the home care nurse: when a stroke patient returns home from the hospital, everyone in the patient's social environment (children, neighbours, family members, friends) is affected by the changes which have occurred, one way or another. Some people may find it difficult to relate to the patient and his/her family. Looking back, who were the persons that were of greatest help to you?"

Each participant is given a piece of paper with a picture of a pie. They are asked to divide the pie into pieces corresponding to the quantity of support family caregivers experienced from (1) their children, (2) neighbours, colleagues or fellow-caregivers (3) professional helpers and (4) other family members and (5) friends.

The participants explain how they have divided their pies. This provides the basis for a discussion of unfulfilled and fulfilled wishes with respect to social support. Coping strategies are sought that may help balance wishes and reality. At the end of the session the home care nurse underlines those existing social contacts of the participants that are valuable to them.

### Example 2:

Example two is taken from the session 'How to ask for help?' The goal of this exercise is to avoid burnout and to offer a tool to facilitate assertive behaviour.

Introduction by the home care nurse:

"It is not always easy to ask for help. Most people do not ask for help until they have exhausted every possibility for managing on their own. However, it may be better to save your strength by asking for help at an early stage. It is better to avoid accepting help that is offered reluctantly. The way in which you ask for help may influence the probability of receiving support."

This exercise may be introduced by role-play, with the family caregiver asking for assistance from a helping person from his/her network. To evaluate the effects of the role-played exercise, use similar questions to those that follow: (1) what kind of help did you want? (2) What feelings did you experience when you asked for help (anger, humiliation, and determination)? (3) Do you believe you will get the help? (4) How difficult was it for you to ask for help? (5) Who has any suggestions for alternative ways of asking for help?

Next, the home care nurse distributes a sheet of paper with advice on how to ask for help:

- What do you really want from the helper?
- Which person or institution can give you the help you need?
- Start your request for help with the word 'I' and continue to put your question clearly and decisively.
- Analyse if the helping person is able and willing to honour your request.
- At the end of the conversation repeat what has been agreed.
- Make a note of whom you have spoken with and when this contact took place.
- If the person cannot answer your question or is not able to offer help, ask him/her for advice about what you can do to get the help you want.

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